

# **Personal Health Information: Issues, Barriers and Concerns**

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**National Health Information  
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# What is Optum?

- **Leader in health/well-being services**
- **Mission: *educate/empower individuals, improve quality of life***
- **16+million covered lives**
- **40+ health plans [also employers, associations, public/private sector]**
- **450+ Nurses and Counselors**

# Optum:

- **6 call centers nationwide [1 Hispanic]**
- **NurseLine**
- **Assistance**
- **Care24 and Care24 Connect**
- **Health Forums**
- ***Taking Care* Newsletters and Books**

# **Optum's Integrated Access Points:**

- **Telephone 24 x 7**
- **In-Person**
- **Print**
- **Audiotape Library**
- **Internet**

# Information Demands and Individual Privacy:

- **Growing organizational demand for data**  
*[epidemiology, research, population studies, societal needs]*
- **Legal and ethical requirements seek to balance this demand with the individual's right to privacy**

# Barriers:

- **Public does not understand that confidentiality is typically protected by degree**
- **Difficult to manage public expectations about confidentiality**
- **Lack of consistency across disciplines, states and legal jurisdictions, internationally**

# **Barriers continued:**

- **Noncongruence on confidentiality between patients, the public, providers/therapists**
- **Public relies on codes of professional ethics without understanding them or the public's legal rights in the event of a breach**

# Barriers continued:

- Changes in the concept of confidentiality over time [individual has evolved to societal]
- Continuum in the concept now [*absolute; client consent to disclosures; disclosure without client consent (as in duty to warn); sharing of data among 3rd party payers and providers*]

# **Barriers [Providers]:**

- **Personal ethics which might conflict with professional ethics and clients' interests**
- **Group therapy and informing family members [enlarges # of people with information]**
- **Untrained/unsupervised clergy and others doing therapy**

# **Barriers [Society at Large]:**

- **When community must be protected from communicable diseases or those dangerous to self or others**
- **In the workplace: disease detection, health screening, genetic testing and inappropriately informing employers**

# **Barriers [In the Law]:**

- **Inconsistent, incomplete legal and ethical guidelines**
- **Conflicting needs of medical and law enforcement**
- **Subpoenas of medical researchers as witnesses**
- **Piecemeal legal solutions to problems with confidentiality**

# **Barriers [For Researchers]:**

- **Questions about data ownership, data storage, consent to retrieve and use data**
- **Computerized databases as potential threats to confidentiality**

# **Barriers [For Managers]:**

- **Accountability efforts [quality standards reviews and peer review mechanisms]**
- **Illegal and unethical uses of health risk assessment and screening data**

# **Barriers [Special Settings]:**

- **Vulnerable populations [minors/infants, incompetent adults, intoxicated people, medical emergencies, those in group/family therapy, those who are a danger to self or others]**
- **3rd party payers with access to databases**

# **Barriers [Special Settings]:**

- **Threats to confidentiality in small groups with overlapping personal/professional boundaries**
- **Public exhibitions of works of art and music therapy**

# **Barriers [Special Settings]:**

- **Compromised confidentiality in bitter child custody cases**
- **Adolescents seeking therapy or medical care with/without parental knowledge**
- **Around impending death of a patient or after the death [what to disclose to family?]**

# **Dark Side of Confidentiality:**

- **May conceal professional misconduct or incompetence, poor quality or inappropriate care or cases of damaging stereotyping of clients**
- **May protect clients who lie and deceive [lie to insurance companies or lie to sexual partners]**

# **Forces that currently enhance confidentiality:**

- **Hippocratic Oath**
- **Weight of tradition and public's perception**
- **Codes of ethics in disciplines**
- **Legal protections**
- **Separating the treating therapist from the prosecutorial/expert witness therapist**

# How to Clarify Confidentiality:

- **Confidentiality: complex, gray area, dynamic concept**
- **Providers/therapist must manage expectations very clearly/concisely and in layman's language for different literacy levels/abilities to comprehend [limits of confidentiality]**
- **Lay out when, if and under what circumstances confidentiality might be compromised**

# **Solutions:**

- **Control access to information on a need-to-know basis only**
- **Strip data of identifiers**
- **Aggregate information for research purposes**
- **Develop clear policies and procedures**

# Solutions:

- **Must differentiate between emergent and non-emergent events**
- **Must make the case that sometimes “Big Brother” can do good work**
- **Must make the case that we need to collect data to do a better job [e.g. race/ethnicity data and what works/doesn't work---therapy, medical care]----what happens to us as a society without research data?**

# How Optum Protects Clients:

- UHG is a member of AAHP and follows “AAHP Guidelines for Consumer Information in an E-Health Environment”
- Optum is a member of The Partnership for Prevention and is providing input to its “Disease Prevention, Health Promotion and Privacy of Health Information” draft document